Slide 1: Decision making when clinical evidence is limited: Palliative chemotherapy for cancer

Anthony Back, MD University of Washington Fred Hutchinson Cancer Research Center Seattle, Washington

Slide 2: The problem

- 33 yo man with metastatic melanoma sp multiple regimens
- Discussing possibility of another therapy
- How do they see this decision?

Slide 3: Why do patients with advanced cancer continue to choose chemotherapy?

- Even when evidence is absent, or indicates low benefit, or suggests potential harm, many patient continue to choose palliative chemotherapy
- Consequences: patient suffering, high costs
- Increase in anticancer therapy driving more use of chemotherapy near the end of life, despite improvements in palliative care

Slide 4: Why?

- Existing analyses focus on decision making
- Measured: parameters of decision making
 - o Information
 - Weighing benefits & burdens
 - Examining concordance between patients and physicians
- Framework: model of shared decision making

Slide 5: Was the patient informed?

- Audio recording interview studies of consent conversations for phase 1
 - o Important information omitted (e.g. prognosis)
 - o Info explained but interpreted incorrectly by patients (e.g. supportive care)
- Physicians use "persuasion": "promising" "novel" "we're excited" "out of options"
 - Decision-making was 'implicit' (unstated assumptions that patient would enroll)

Slide 6: Did the patient weigh the benefits and burdens differently?

- Patients are willing to choose a palliative therapy for a level of benefit that is lower that what clinician would tolerate
- Patients would have toxic treatment for...
 - o 1% chance of cure

- o 10% chance of symptom relief
- Physicians would have toxic treatment for...
 - o 50% chance of cure
 - o 75% chance of symptom relief

Slide 7: Did the patient believe what the doctor said?

- Audiorecording study of patients coming for a stem cell transplant N = 232
 - having the physician give an explicit percentage about cure does NOT correlate with patient/physician concordance after the visit
 - 1/3 overestimated chance of cure by >20%
 - Information embedded in dense monologue in most cases (median 80 min consults, 9 recommendations)
 - o "I felt like I was in bone marrow 101 or something"

Slide 8: Question: do patients see these discussions as 'decisions'?

Slide 9: "Chat History": a personal account

- Clark: Dr. Kitano called
- Me: to say what?
- Clark: email coming
 - um, the message said that that she understands our concerns and that they are still able to provide us the original treatment and just wanted to talk to us more about it
- Me: WHAT?
- Clark: she still wants us to keep our appt thur
- Me: oh my god

Slide 10: "Chat History": decision making?

- Me: got her email
 - o my god
 - they're going to do it
- Clark: whenever Kitano does something totally rad play that 'Are you ready for the sex girls' song from Revenge of the Nerds in my head
- Me: HAHAHAHA
- Clark: I should make her a mix tape

Slide 11: Patients don't see another regimen of palliative chemo as another decision?

- Qualitative study of 13 pts with metastatic colon and pancreas cancer
- "Treatment" was seen as a continuous process in which options changed over time and options remained open

• "One-off decision making is rarely the central activity"—physician provides continuous information about a changing situation with little decision 'closure'

Slide 12: Are patient experiences about approaching end of life accessible?

- Internet discussions tend to be fueled and dominated by long term survivors
- Little discussion and few stories of patients and families wrestling with complex medical decisions, finding a way to approach death and not trying every last treatment

Slide 13: New approaches

- Communication strategies that reformulate the context of the decision
- Adaptation strategies for dealing with fear so that future can be considered in a new light
- Reformulating big decisions as a series of smaller discussions to reduce urgency

Slide 14: More new approaches

- Rethinking use of prognostic information and how to use it; looking at patterns of irrationality
- Using narrative approaches to influence patient thinking and understanding

Slide 15: Example: communication strategy

- "We're in a different place"
- Suggested by participants in qualitative study in which they listened to audio recordings of an oncologist talk to a patient
- Notable attributes: "soft start", allows construction of new context (not the same benefit as when we last made this sort of decision)
- About directionality rather than decisions

Slide 16: Example: desensitization

- "We will reach a time when the chemo is not working. What have you been thinking about that moment?"
- Expert practice used by clinicians in early integration of palliative care study
- Notable: making the moment of treatment failure a predictable thing for which planning and preparation can be done

Slide 17: Example: using irrationality

- Suggestion: Having choices that no one uses can influence behavior—allow the patient to take "the middle road"
- Example: deliberate framing of chemo decision
 - o Therapy with possible fatal side effects, no benefit
 - Therapy to continue current QOL as long as possible

o Therapy to prepare for death

Slide 18: Physician acquisition of communication skills

- 55% of the 7 eligible physicians acquired the communication skill "Assesses patient perception"
- 40% of the 101 eligible physicians acquired the communication skill "Requests permission"
- 52% of the 8 eligible physicians acquired the communication skill "Uses the word 'cancer"
- 66% of the 5 eligible physicians acquired the communication skill "Silent for 10 seconds after giving news"
- 73% of the 5 eligible physicians acquired the communication skill "Makes empathic statement after giving news"
- 38% of the 8 eligible physicians acquired the communication skill "Asks for patient's reaction to news"
- 53% of the 4 eligible physicians acquired the communication skill "Summarizes follow-up plan"

Slide 19: Aspects receiving little attention

- Affective tone of the context of the decision: 'hot' and 'cold' states
- Cognitive load: manageable or exhausted?
- Social influences: presence of extramedical considerations big or small?
- Reciprocality of exchange: shows mutuality or not?